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ABSTRACT

The booklet provides background information on the diagnosis and characteristics of autism. A chart portrays the signs and symptoms, followed by the definition of the syndrome by the National Society For Children and Adults with Autism. Associated features are noted along with information on age of onset, etiology, incidence and sex ratio, complications, and differential diagnosis. The diagnostic criteria put forth by the Diagnostic and Statistical Manual of Mental Disorders (Third Edition) DSM-III are also presented in terms of associated features, age at onset, course, impairment, complications, prevalence, sex ratio, predisposing factors, familial pattern, and differential diagnosis. Typical behaviors, such as unusual response to sound and unusual speech patterns, are listed. Programmatic requirements, including early diagnosis and appropriate intervention, highly structured programs, and comprehensive home programming/parent training, are summarized. A brochure entitled "Questions and Answers," which presents practical questions and answers on autism is attached. (CL)

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AUTISM:
Basic Information

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INTRODUCTION

As coordinators of the Autism Outreach Project, we have found a general lack of knowledge regarding the identifying characteristics and diagnostic criteria of the syndrome of autism. This impedes the accurate diagnosis of children with autism, condemning them to fit into existing programs which are rarely geared to meet their complex needs. (This lack of identification also prohibits accurate program planning at the state level.) Diagnosis is the cornerstone and a necessary first step to *appropriate* service provision and long range program planning. This booklet contains the two widely used sets of diagnostic criteria along with other relevant basic information. We dedicate this booklet to infants with autism in hope that they will reap the rewards of *early diagnosis* and *effective intervention*.

April, 1986

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AUTISM FACT SHEET

- Autism Is A Lifelong Developmental Disability
- Autism Usually Appears During The First Three Years Of Life
- Autism Is Defined And Diagnosed Behaviorally
- Developmental And Symptom Patterns Among Individuals With Autism Can Be Quite Variable
- Symptoms Of Autism Fall Into 4 Categories Of Behavior
  - Disturbances in the rate and appearance of physical, social and language skills
  - Abnormal or unusual responses to sensory stimuli
  - Abnormal ways of relating to people, objects or events
  - Severely impaired language acquisition and comprehension
- Autism Is 4 Times More Common In Males Than Females
- Autism Affects 5 To 15 Of Every 10,000 Births
- Autism Is Found Throughout The World In Families Of All Racial, Ethnic And Social Backgrounds
- The Cause Of Autism Is Not Known; However, There Is Much Support That Autism Is A Biologically Based Disorder
- No Known Factors In The Psychological Environment Of A Child Have Been Shown To Cause Autism
- About A Third Of All Individuals With Autism Develop Seizures
- IQ Testing Shows That 60% Of Individuals With Autism Have Scores Below 50, 20% Between 50 and 70, and 20% Greater Than 70
- Many Individuals With Autism Have Distinct Skills (Splinter Skills) In Some Areas (Many Times In Music, Mathematics, Mechanical, Spatial Concepts) But Perform Very Poorly In Other Areas
- Autism Is TREATABLE – Early Diagnosis and *Appropriate* Intervention Are Vital To The Future Development Of The Child
- Highly Structured, Skill-Oriented Data-Based Teaching And Treatment Programs, Based Upon The Principles Of Applied Behavior Analysis Are The Most Effective In Improving The Skills And Behavior Of Individuals With Autism. Such Training Must Be Tailored To The Specific Needs Of The Individual, And Must Be Delivered In A Comprehensive, Consistent, Systematic And Coordinated Manner
- Individuals With Autism Live Through A Normal Life Span

SIGNS AND SYMPTOMS OF AUTISM

The following chart, developed by the National Society for Children and Adults with Autism (NSAC), visually portrays the more important signs and symptoms of autism. If a child exhibits 7 or more of these behaviors and if the behavior is constant and age inappropriate, further evaluation is recommended.

(The severe form of the syndrome may include self-injurious, self-stimulatory [highly repetitive, unusual behavior such as body rocking, hand flapping, etc.] and aggressive behavior.)

NATIONAL SOCIETY FOR CHILDREN AND ADULTS WITH AUTISM DEFINITION OF THE SYNDROME OF AUTISM*

ESSENTIAL FEATURES: Autism is a behaviorally defined syndrome. The essential features are typically manifested prior to 30 months of age and include:

(1) Disturbances of developmental rates and sequences. Normal coordination of the three developmental pathways (motor, social-adaptive, cognitive) is disrupted. Delays, arrests and/or regressions occur among or within one or more of the pathways:

(a) within the motor pathway: for example, gross motor milestones may be normal, while fine motor milestones are delayed;

(b) between pathways: for example, motor milestones may be normal, while social-adaptive and cognitive are delayed;

(c) arrests, delays, and regressions: for example, motor development may be normal until age 2 when walking stops; some cognitive skills may develop at expected times, while others are delayed or absent; imitative behavior and/or speech may be delayed in onset until age 3, followed by rapid acquisition to expected developmental level.

(2) Disturbances of responses to sensory stimuli. There may be generalized hyperreactivity or hyporeactivity, and alternation of these two states over periods ranging from hours to months. For example:

(a) visual symptoms: these may be close scrutiny of visual details, apparent nonuse of eye contact, staring, prolonged regarding of hands or objects, attention to changing levels of illumination;

(b) auditory symptoms: these may be close attention to self-induced sounds, nonresponse, or overresponse to varying levels of sound;

(c) tactile symptoms: these may be over- or under-response to touch, pain, and temperatures, prolonged rubbing of surfaces, and sensitivity to food textures;

(d) vestibular symptoms: these may be over- or under-reactions to gravity stimuli, whirling without dizziness, and preoccupation with spinning objects;

**This definition has been adopted by the New Jersey Department of Human Services.*

(e) olfactory and gustatory symptoms: these may be repetitive sniffing, specific food preferences, and licking of inedible objects;

(f) proprioceptive symptoms: these may be posturing, darting-lunging movements, hand flapping, gesticulations and grimaces.

(3) Disturbances of speech, language-cognition, and nonverbal communication. Symptoms may include:

(a) speech: for example, mutism, delayed onset, immature syntax and articulation, modulated but immature inflections;

(b) language-cognition: for example, absent or limited symbolic capacity, specific cognitive capacities such as rote memory and visual-spatial relations intact with failure to develop the use of abstract terms, concepts, and reasoning; immediate, delayed, negative echolalia with or without communicative intent; nonlogical use of concepts; neologisms;

(c) nonverbal communication: for example, absence or delayed development of appropriate gestures, dissociation of gestures from language, and failure to assign symbolic meaning to gestures.

(4) Disturbances of the capacity to relate appropriately to people, events, and objects, manifested by failure to develop appropriate responsivity to people and assignment of appropriate symbolic meaning to objects. For example:

(a) people: absence, arrests and/or delays of smiling response, stranger anxiety, anticipatory response to gestures, playing "peek-a-boo," playing "patty-cake," and waving "bye-bye," reciprocal use of eye contact and facial responsivity, and appropriate reciprocal responsiveness to physical contact; failure to develop a relationship with significant caretakers or excessive reliance on caretakers. For example, caretakers may be treated indifferently, interchangeably, with only mechanical clinging, or with panic on separation. Cooperative play and friendships (usually appearing between 2 and 4) may not develop. Expected responses to adults and peers (usually appearing between 5 and 7) may develop, but are superficial, immature, and only in response to strong social cues;

(b) objects: absent, arrested and/or delayed capacities to utilize objects and/or toys in an age-appropriate manner and/or to assign them symbolic and/or thematic meaning. Objects are often used in idiosyncratic, stereotypic and/or perseverative ways. Interference with this use of objects often results in expressions of discomfort and/or panic;

(c) events: there may be a particular awareness of the sequence of events and disruption of this sequence may result in expressions of discomfort and/or panic.

A SYNOPSIS OF INFORMATION RELATING TO THE SYNDROME OF AUTISM

I. ASSOCIATED FEATURES:

Associated clinical features vary with age and include other disturbances of thought, mood and behavior. Mood may be labile; crying may be unexplained or inconsolable; there may be giggling or laughing without identifiable stimuli. Delusions and hallucinatory experiences have been reported. There may be a lack of appreciation of real dangers, such as moving vehicles and heights as well as inappropriate fears. Self-injurious behaviors, such as hair pulling and hitting or biting parts of the body, may be present and stereotypic and repetitive movements of limbs or the entire body are common.

Current research estimates are that approximately 60% of autistic children have measured IQ's below 50; 20% between 50-70; and 20% of 70 or more. The majority show extreme variability of intellectual functioning on formal IQ testing. They perform poorest on tasks requiring abstract thought, symbolism or sequential logic, and best on those assessing manipulative or visual-spatial skills and rote memory.

Recent studies indicate that the incidence of EEG abnormalities increases with age as does the possible onset of seizures.

II. IMPAIRMENT:

The syndrome is severely incapacitating. Periodic medical, neurological, psychological, educational and behavioral reassessments are necessary. One must monitor the course of the syndrome to keep treatment planning apace with physiological and behavioral changes. Special educational facilities are almost always required. Behaviorally structured, functional, individualized programs have been demonstrated to be most helpful. Counseling families regarding total living planning is often desirable. Individual supportive psychotherapy and symptomatically targeted pharmacologic therapy may enhance social-adaptive functioning in selected persons. The severe form of the syndrome may include the most

extreme forms of self-injurious, repetitive, highly unusual and aggressive behaviors. Such behaviors may be persistent and highly resistant to change, often requiring unique management, treatment, or teaching strategies.

III. AGE OF ONSET:

The exact age of onset is unknown, but symptoms have been reported and observed during the first months of life. Families may be unaware of early symptoms until the child fails to pass major developmental milestones (i.e., onset of walking, speech, socialization with peers). They may then date the onset of the syndrome to these missed milestones, whereas careful history taking may reveal that subtle symptoms were present earlier.

IV. ETIOLOGY:

The symptoms are best explained as expressive of a physical dysfunction within the central nervous system (CNS) – the exact nature and type of which has yet to be determined. This physical dysfunction of the CNS occurs independently or in association with other disorders which directly affect the central nervous system (i.e., maternal rubella, PKU, Down's syndrome, epilepsy). In such cases, the diagnosis of autism is primary, and the coexisting organic condition, secondary.

V. INCIDENCE AND SEX RATIO:

The syndrome has been identified in all parts of the world. It is very rare, with an incidence of approximately 5-15 per 10,000 births. It is found 4 to 5 times more commonly in males.

VI. COMPLICATIONS:

Major complications are self-induced physical injuries, infections related to improper hygiene, dental problems related to persistent bruxism, and physical injuries due to inadvertent exposures.

VII. DIFFERENTIAL DIAGNOSIS:

1. Mental Retardation, Etiology Unknown and Known:

Here developmental delays usually occur in all areas, and developmental sequences (motor, social and cognitive) remain *coordinated*. Responses to sensory inputs, people and objects, and speech and language development are appropriate to the overall developmental level of cognitive functioning.

2. Specific Sensory Deficits (e.g. Deafness, Blindness):

   Here compensatory behaviors may be confused with symptoms indicative of autism (e.g., hyper-reactivity to auditory, proprioceptive and tactile stimuli in blind children [i.e., blindisms]; hyperresponsivity to visual, proprioceptive [i.e., head shaking], and tactile stimuli in deaf children). When auditory and visual deficits are accompanied by mental retardation, speech, language, and the ability to relate to people and objects are appropriate to the overall developmental level of cognitive functioning.

3. Congenital, Developmental, and Acquired Disorders of Central Processing of Language (Aphasias):

   Here disturbances in language development and central processing are not accompanied by disturbances of responses to sensory inputs, disassociation of other developmental courses (motor, social), relatedness to people and objects. Aphasics may imitate and use gestures and other means to communicate symbolic content. If these disorders are accompanied by mental retardation then it must be assessed independently of the disturbances of central processing of language.

4. Sequelae of Physical or Psychological Trauma (e.g., Syndromes, Previously Described as Hospitalism, Maternal Deprivation, Anaclitic Depression, Sequelae of a Chronically Traumatizing Environment):

   Here syndromes include failure to thrive, infantile apathy and withdrawal, physical illnesses secondary to malnutrition or toxin ingestions and physical abuse, specific psychological fixations (psychogenic psychoses, severe neuroses, pathological character development), and all degrees of mental retardation. The pattern of symptoms and developmental delays are specific to the syndromes described, are related to specific etiologic factors in psychological and social environments, and respond to specific therapies if instituted before permanent changes have resulted.

5. Schizophrenia, Childhood Type:

   Here the disorder is characterized by the presence of a thought disorder (see the definition of thought disorder in the American Psychiatric Association's *Diagnostic and Statistical Manual*, Third Edition). The schizophrenic child is likely to have a language base and to utilize speech to communicate even irrational thoughts. The autistic child by contrast manifests a general failure to utilize speech to communicate. Likewise, the schizophrenic

child is likely to experience distorted social relationships while the autistic child is generally unable to establish social relationships.

6. Degenerative Organic Brain Syndrome (e.g., Schilder's Disease, Heller's Syndrome) With or Without Mental Retardation:

   Here the clinical course is characterized by progressive regressions in all or some areas of development (motor, social-adaptive, and cognitive). In the early stages, these regressions may mimic symptoms indicative of autism but are distinguishable by their relatively specific times of onset, characteristic signs and symptoms on neurological, psychological, and cognitive testing, and unremitting deteriorating course.

VIII. PREDISPOSING FACTORS:

None known.

IX. FAMILY FACTORS:

None known. The syndrome has been identified in all parts of the world. Recent studies have revealed no correlation between autism and parental psychopathology.

DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS (THIRD EDITION) DSM-III – DIAGNOSTIC CRITERIA

299.0x INFANTILE AUTISM

The essential features are a lack of responsiveness to other people (autism), gross impairment in communicative skills, and bizarre responses to various aspects of the environment, all developing within the first 30 months of age. Infantile Autism may be associated with known organic conditions, such as maternal rubella or phenylketonuria. In such cases the behavioral syndrome Infantile Autism should be recorded on Axis I, and the physical disorder, on Axis III.

The relationship of this category to Schizophrenia is controversial. Some believe that Infantile Autism is the earliest form of Schizophrenia, whereas others believe that they are two distinct conditions. However, there is apparently no increased incidence of Schizophrenia in the families of children with Infantile Autism, which supports the hypothesis that the two disorders are unrelated.

The failure to develop interpersonal relationships is characterized by a lack of responsiveness to and a lack of interest in people, with a concomitant failure to develop normal attachment behavior. In infancy these deficiencies may be manifested by a failure to cuddle, by lack of eye contact and facial responsiveness, and by indifference or aversion to affection and physical contact. As a result, parents often suspect that the child is deaf. Adults may be treated as interchangeable, or the child may cling mechanically to a specific individual.

In early childhood there is invariably failure to develop cooperative play and friendships; but, as the children grow older, greater awareness of and attachment to parents and other familiar adults often develop. Some of the least handicapped may eventually reach a stage where they can become passively involved in other children's games or physical play such as running with other children. This apparent sociability is superficial, however, and can be a source of diagnostic confusion if mistaken for social relatedness when the diagnosis is made retrospectively.

Impairment in communication includes both verbal and nonverbal skills. Language may be totally absent. When it develops, it is often char-

acterized by immature grammatical structure, delayed or immediate echolalia, pronominal reversals (use of pronoun "you" when "I" is the intended meaning), nominal aphasia (inability to name objects), inability to use abstract terms, metaphorical language (utterances whose usage is idiosyncratic and whose meaning is not clear), and abnormal speech melody, such as questionlike rises at ends of statements. Appropriate nonverbal communication, such as socially appropriate facial expressions and gestures, is often lacking.

Bizarre responses to the environment may take several forms. There may be resistance and even catastrophic reactions to minor changes in the environment, e.g., the child may scream when his or her place at the dinner table is changed. There is often attachment to odd objects, e.g., the child insists on always carrying a string or rubber band. Ritualistic behavior may involve motor acts, such as hand clapping or repetitive peculiar hand movements, or insisting that fixed sequences of events precede going to bed. The fascination with movement may be exemplified by staring at fans, and the child may display inordinate interest in spinning objects. Music of all kinds may hold a special interest for the child. The child may be extremely interested in buttons, parts of the body, playing with water, or peculiar rote topics such as train schedules or historical dates. Tasks involving long-term memory, for example, recall of the exact words of songs heard years before, may be performed remarkably well.

Associated features. Mood may be labile; crying may be unexplained or inconsolable; there may be giggling or laughing without identifiable cause. There is often underresponsiveness or overresponsiveness to sensory stimuli, such as light, pain, or sound. Real dangers, such as moving vehicles and heights, may not be appreciated. Peculiar nervous habits, such as hair pulling or biting parts of the body, are sometimes present. Rocking or other rhythmic body movements also occur.

About 40% of children with the disorder have an IQ below 50; only 30% have an IQ of 70 or more. These children show extreme variability in intellectual functioning; they are often untestable on verbal tasks, and when testable, performance is worst on tasks demanding symbolic or abstract thought and sequential logic. However, tasks requiring manipulative or visual-spatial skills or immediate memory may be performed well.

Age at onset. By definition, the age at onset is always before 30 months. However, it may be difficult to establish age at onset retrospectively unless those who cared for the child during the early years are able to give accurate information about language development, sociability, and play. Parents of only children may be unaware of the problems until the

child is observed with other children. The parents may then date the age at onset from that point, although a careful history will usually reveal that the abnormalities were present earlier.

Course. The disorder is chronic. Some of these children eventually are able to lead independent lives, with only minimal signs of the essential features of the disorder; but often the social awkwardness and ineptness persist (Residual State). Overall, one child in six makes an adequate social adjustment and is able to do some kind of regular work by adulthood; another one in six makes only a fair adjustment; and two-thirds remain severely handicapped and unable to lead independent lives. Factors related to long-term prognosis include IQ and development of language skills.

Impairment. The disorder is extremely incapacitating, and special educational facilities are almost always necessary.

Complications. The major complication is the development of epileptic seizures to an underlying physical disorder; about 25% or more cases develop seizures in adolescence or early adult life. Most of the children with an IQ below 50 develop seizures, but only very few of those with normal intelligence do so.

Prevalence. The disorder is very rare (2-4 cases per 10,000). It is apparently more common in the upper socioeconomic classes, but the reason for this is not clear.

Sex ratio. The disorder is about three times more common in boys than in girls.

Predisposing factors. Maternal rubella (especially when associated with infantile deafness or blindness), Phenylketonuria, encephalitis, meningitis, and tuberous sclerosis are among the predisposing factors. In the past, certain familial interpersonal factors were thought to predispose to the development of this syndrome, but recent studies do not support this view.

Familial pattern. The prevalence of Infantile Autism is 50 times as great in siblings of children with the disorder than in the general population.

Differential diagnosis. In Mental Retardation there are often behavioral abnormalities similar to those seen in Infantile Autism. However, the full syndrome of Infantile Autism is rarely present. When both disorders are present, both diagnoses should be made. In Schizophrenia occuring in childhood there are oddities of behavior; but typically there are hallucinations, delusions, and loosening of associations or incoherence, which are

not present in Infantile Autism. In Childhood Onset Pervasive Developmental Disorder, the age at onset is later than in Infantile Autism and the full syndrome of Infantile Autism is not present. In children with hearing impairments there will be a history of responding consistently only to very loud sounds, whereas in Infantile Autism the response to sounds is inconsistent. An audiogram can rule out the possibility of hearing impairment. In Developmental Language Disorder, Receptive Type, the children generally make eye contact and will often try to communicate appropriately by means of gestures, whereas in Infantile Autism there is a pervasive lack of responsiveness.

Diagnostic criteria for Infantile Autism

A. Onset before 30 months of age.

B. Pervasive lack of responsiveness to other people (autism).

C. Gross deficits in language development.

D. If speech is present, peculiar speech patterns such as immediate and delayed echolalia, metaphorical language, pronominal reversal.

E. Bizarre responses to various aspects of the environment, e.g., resistance to change, peculiar interest in or attachments to animate or inanimate objects.

F. Absence of delusions, hallucinations, loosening of associations, and incoherence as in Schizophrenia.

299.00 INFANTILE AUTISM, FULL SYNDROME PRESENT

Currently meets the criteria for Infantile Autism.

299.01 INFANTILE AUTISM, RESIDUAL STATE

Diagnostic criteria for Infantile Autism, Residual State

A. Once had an illness that met the criteria for Infantile Autism.

B. The current clinical picture no longer meets the full criteria for Infantile Autism, but signs of the illness have persisted to the present, such as oddities of communication and social awkwardness.

SYNOPSIS OF DIAGNOSTIC CRITERIA OF AUTISM*

DSM-III**	NSAC***
1. Severe language deficiency	1. Language deficiency
2. Pervasive lack of interpersonal responsiveness	2. Disturbed interpersonal relationships
3. Bizarre responses to environmental stimulation	3. Inconsistent responses to sensory stimulation
4. Absence of hallucinations and delusions	4. Developmental delays
5. Age of onset prior to 30 months of age	5. Onset prior to 30 months

* Reprinted from: Powers, M.D. & Handleman, J.S. (1984). *Behavioral Assessment of Severe Developmental Disabilities.* Rockville, MD: Aspen Publication.

** Diagnostic and Statistical Manual of Mental Disorders, Third Edition

*** National Society for Children and Adults with Autism

A KEY TO AUTISTIC BEHAVIORS*

Many of the behavioral and emotional problems shown by individuals with autism stem directly from difficulty in understanding and relating to the world around them. For example:

- Their response to sound may be unusual, often causing people to think an autistic child is deaf. An autistic child may appear not to hear a loud noise like a siren, but be totally fascinated with the sound of crumpling paper. Some sounds distress the child so that he will cringe and cover his ears.
- An autistic child usually ignores speech, apparently unaware it has meaning. It may take years for a child to respond to his own name or learn that certain objects have specific names. The child may learn to follow simple instructions (the fewer words the better) but be confused by a long sentence.
- Some never speak. Others learn a few words, almost always later than usual. They show typical but unusual patterns of speech. Some try to communicate by repeating what they have just heard; this is called echolalia. If you ask, "Do you want a cookie?" and the child answers "Do you want a cookie", the chances are that he wants one. Some show delayed echolalia and are able to repeat verbatim something heard in the past. Some have a great repertory of television commercials. Some learn to say meaningful words and phrases of their own, but sentences may be abbreviated, words confused and collapsed, letters reversed within words, or words within sentences. They have trouble with prepositions and pronouns, confusing "you" with "I". Some talk quite successfully but express themselves like a telegram. Others learn to talk fluently and correctly about a wide range of subjects.
- They have trouble with pronunciation and voice tone. They miss ends of words or use only pieces and frequently cannot produce a smooth flow of words. Correct vocal inflection is rare.
- The way they see often seems to be as confused as the way they hear. They may be fascinated by shiny objects, upset by bright lights, or look at an object only when it is moving. They appear to recognize shapes only by the general outline, suggesting they may not be using the part of the eye that sees fine detail. They tend to be confused by complicated and rapidly changing sights.
- Autistic children do not seem able to communicate with gestures to

show what they want, though they will often push your arm towards something they want. They may have to be taught to point and to smile.

- They often learn about the world not so much by seeing and hearing as by using touch and smell and taste to explore. They may enjoy games that provide what neurologists call vestibular stimulation, like being tossed in the air, even though they don't otherwise like to be touched. Some appear insensitive to cold, heat or pain, or very sensitive, or they may alternate between the extremes.
- Many have unusual body movements: walking on tiptoe, flapping hands and arms, rocking back and forth in a chair, or spinning around without becoming dizzy. When a child is meaningfully occupied these movements tend to disappear. Their movements are immature, though some may be skillful climbers and balancers. They have trouble copying movements like hopping and skipping. They may confuse back and front, left and right.
- They are usually aloof and withdrawn, especially when young.
- They resist change.
- They develop fears of harmless objects but are unaware of real dangers.
- Their behavior in social situations is inappropriate, often embarrassing to their parents.
- They are rarely able to play and explore like a normal child. Toys to them are only what they are: A doll does not suggest to them a human being or a toy car a real car.
- Sometimes autistic children show special abilities that are as baffling as the gaps in their development. Some have a fantastic memory for detail and trivia. Some have advanced musical ability and can play complex musical passages even if they can't read music. Some show a superhuman sense of balance, and scare their parents with such feats as walking along the tops of fences. Some can tell you instantly the day of the week corresponding to any past or future date. Some are gifted in mathematics.

* Reprinted from: How They Grow: A Handbook For Parents of Young Children With Autism (1984) NSAC, The National Society for Children & Adults With Autism.

SUMMARY OF PROGRAMMATIC REQUIREMENTS

An overview of research, the 1982 report of the New Jersey State Task Force on Autism and the 1981 report of the Committee to Study the Effectiveness of Programs for Autistic Children (NJ Department of Education, #200.2) reveals that:

- EARLY DIAGNOSIS AND APPROPRIATE INTERVENTION are vital to the development of individuals with autism;
- HIGHLY STRUCTURED, SKILL-ORIENTED, TEACHING AND TREATMENT PROGRAMS (programs which simultaneously address skill deficits and problem behaviors by utilizing both skill building and behavior reduction techniques throughout the day), based upon the principles of applied behavior analysis are the most effective in improving the skills and behavior of individuals with autism;
- PROGRAMS MUST BE TAILORED TO THE SPECIFIC NEEDS OF THE INDIVIDUAL and delivered in a comprehensive, consistent, systematic, and coordinated manner. Since many children and adults with autism have deficits in many skill areas, providing comprehensive instruction is necessary;
- PROGRAMS SHOULD BE DATA-BASED. Behaviors should be operationally defined. Teaching and treatment procedures should be outlined. The occurence of behavior should be recorded before (baseline), during, and after (follow-up) the implementation of teaching and treatment procedures. A summary (i.e., graphs, charts) of data should be provided. Data-based programs permit objective evaluation of the effects of the intervention. On the basis of these data, programs should be revised as needed to assure continued progress;
- PROGRAMS SHOULD USE INDIVIDUALIZED MOTIVATIONAL SYSTEMS (i.e., primary systems [food], token systems, behavior contracts, etc.) and appropriate reinforcement schedules (i.e., continuous, fixed ratio, etc.). Motivational systems are based upon the learning principle that individuals tend to repeat or increase behaviors which are followed by positive consequences;
- TEACHING AREAS SHOULD BE STRUCTURED, ORGANIZED, AND DISTRACTION-FREE ENVIRONMENTS WHICH INCORPO-

RATE INTENSIVE ONE-TO-ONE AND SMALL GROUP SESSIONS. SCHEDULES OF ROUTINES AND ACTIVITIES SHOULD PROCEED SMOOTHLY AND RELIABLY WITHIN AND ACROSS DAYS. TIME SPENT "WAITING" SHOULD BE KEPT TO A MINIMUM. Classrooms should be equipped with one-way mirrors for observation. For those individuals ready for transition to other settings, larger group sessions ("normal" classrooms) should be provided;

- TO PROVIDE THE CONSISTENCY NECESSARY FOR GENERALIZATION and maintenance of skills and appropriate behavior:
  - Programs should be offered on a FULL-DAY, YEAR-ROUND BASIS from preschool through adulthood;
  - INDIVIDUALS SHOULD BE TAUGHT IN MULTIPLE SETTINGS, by multiple therapists using a variety of stimuli;
  - A COMPREHENSIVE HOME PROGRAMMING/PARENT TRAINING PROGRAM should be provided to foster coordination of day and evening programming. Parents should be provided with support groups and extensive in-home behavior management training, which also gives parents a method of coping with many of the child's behavior problems;
- All personnel involved with individuals with autism should be extensively, specifically TRAINED AND CONTINUOUSLY EVALUATED. On-going skill-based staff training and evaluation are necessary to help ensure staff excellence.

BRIEF READING LIST

Available From:

NSAC Bookstore
1234 Massachusetts Ave., NW
Suite 1017
Washington, DC 20005
(202) 783-0125

1 Autism: A Reappraisal of Concepts and Treatment. Rutter/Schopler. $29.50

26 Early Childhood Autism. Wing. $12.75

#131 Educating and Understanding Autistic Children. Koegel et.al. $27.50

#138 Autism: Diagnosis, Instruction, Management and Research. Gillian. $26.75

#148 The Biology of the Autistic Syndromes. Coleman/Gillberg. $36.95

Other Sources

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AUTISM

Questions and Answers

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WHAT IS AUTISM?

Autism is a lifelong developmental disability *that occurs in approximately 5-15 out of every 10,000 births. It usually occurs within the first three years of life and is 4-5 times more prevalent in boys than in girls. Autism knows no racial, ethnic or social boundaries and is* ***not*** *caused by psychological factors in the child's environment. Children and adults with autism have severe developmental and perceptually-based learning disabilities that make it difficult for them to understand the world around them. A continuum of the symptoms of the disorder may include repetitive, self-stimulatory, extreme self-injurious and/or aggressive behavior.*

WHAT IS A DEVELOPMENTAL DISABILITY?

A developmental disability is a physically or mentally handicapping condition that originates early in life and therefore ***interferes with several aspects of the individual's developmental progress.*** *Such disabilities usually result in multiple handicaps, are expected to be lifelong and require continuing special services to ensure the health, well-being and maximum personal growth of the individual. Autism, cerebral palsy, epilepsy and mental retardation are all developmental disabilities.*

DO THOSE WITH AUTISM ALSO HAVE MENTAL RETARDATION?

Autism can occur by itself or in association with other disorders which affect the function of the brain. These include metabolic disturbances, epilepsy and mental retardation. Research shows that ***80%*** *of the individuals with autism have* ***I.Q. scores below 70.***

WHAT IS THE DIFFERENCE BETWEEN AUTISM AND MENTAL RETARDATION?

Most people with mental retardation show relatively ***even*** *skill development. The individual will usually perform on the same developmental level in all areas of functioning. Individuals with autism typically show* ***uneven*** *skill development with deficits in certain areas, such as speech and language, and distinct skills in other areas, such as music, mathematics and/or spatial arts.*

WHAT CAUSES AUTISM?

While the cause of autism is not known, current research suggests that autism is a ***biologically-based disorder.*** *Autism is associated with other disorders which affect the function of the brain. About one-third of all individuals with autism develop seizure disorders.*

Currently there are no medical tests to diagnose autism. Diagnosis must be based on observations of the individual's behavior by a trained diagnostician. It is important to distinguish autism from mental retardation or other disorders since diagnostic confusion may result in referral to inappropriate and ineffective treatment programs.

IS AUTISM TREATABLE?

Early diagnosis and appropriate intervention are vital *to the future development of a child with autism. Research indicates that individuals with autism respond well to a highly structured, specialized educational program. Training must be tailored to the specific needs of the individual and must be delivered in a consistent, comprehensive and coordinated manner. Programs using applied behavior analysis have proven to be effective in remediating the skill deficits and behavior problems that children and adults with autism typically show.*

SIGNS AND SYMPTOMS OF AUTISM*

- ***Resistant to learning***
- ***Inappropriate laughing and giggling***
- ***No fear of real dangers***
- ***No apparent sensitivity to pain***
- ***Not cuddly***
- ***Sustained odd play***
- ***Little or no eye contact***
- ***Stand-offish manner***
- ***Indicates need by gesturing***
- ***Inappropriate attachments to objects***
- ***Lack of speech***
- ***Acts as deaf***
- ***Spins objects***
- ***Extreme distress for no discernible reason***
- ***Resists change in routine***
- ***Difficulty in mixing with other children***
- ***Uneven gross/fine motor skills***
- ***Marked physical overactivity and/or extreme passivity***

**Individuals with autism may exhibit various combinations of some or all of these signs and symptoms.*

CHARACTERISTICS OF AUTISM

DISTURBANCES IN THE RATE OF APPEARANCE AND DEVELOPMENT OF PHYSICAL, SOCIAL AND LANGUAGE SKILLS

Unlike individuals with mental retardation who typically show developmental delay in all areas, individuals with autism may acquire skills in one area and have delays or an absence of skills in another area. Many parents first notice that something is "wrong" when their child does not reach developmental milestones. Other parents report a regression in their child's normal developmental growth when one day he or she stopped talking, walking or responding to events around them. An individual with autism also may function developmentally on many different levels. He or she may be unable to learn his or her name but be able to do a jigsaw puzzle with ease. Children and adults with autism may have distinct skills in some areas (many times music, mathematics and spatial arts) but perform very poorly in other areas.

DELAY OR ABSENCE OF SPEECH AND LANGUAGE

Some individuals with autism never speak. Although many eventually learn to use at least some sign language or words, their speech is clearly deficient. Abnormalities in speech include echolalia (individual will repeat exactly what is said to him or her), immature speech patterns and poor pronunciation. Some children and adults with autism will indicate needs by gesturing. While many do learn some communication skills, they typically have a very limited understanding of word meanings and abstract ideas.

ABNORMAL RESPONSES TO SENSATIONS

Individuals with autism may overreact or underreact to sensory stimulation from one or more of the senses (sight, smell, hearing, taste, touch, balance). For example, a child may exhibit limited eye contact but may gaze into a bright light for unlimited amounts of time. Many children and adults with autism show an apparent insensitivity to pain, act as though they are deaf and/or show marked physical overactivity or extreme passivity.

ABNORMAL WAYS OF RELATING TO PEOPLE, OBJECTS OR EVENTS

Many parents will speak about their young child with autism as being indifferent to them. Many children with autism may eventually learn to become more responsive to others as they learn to communicate and understand the world around them. Individuals with autism may have inappropriate attachments to objects or sustained, peculiar play activities. For example, a child may spin the wheels on a toy car rather than put it on the floor and push it, or find one shoestring and continually dangle it in front of his or her eyes. An inappropriate attachment to an object may lead to further problems when it is taken away, as individuals with autism can be very resistant to change. This dependence on objects or routines may be very difficult for a family of an individual with autism, since a break in routine could be a major upset to that child or adult.

FOR INFORMATION ON AUTISM AND SERVICES AVAILABLE FOR INDIVIDUALS WITH AUTISM CONTACT THESE AGENCIES:

NATIONAL SOCIETY FOR CHILDREN AND ADULTS WITH AUTISM (NSAC)

1234 Massachusetts Ave., N.W.
Suite 1017
Washington, D.C. 20005
(202) 783-0125

NJ COUNCIL OF ORGANIZATIONS AND SCHOOLS FOR AUTISTIC CHILDREN AND ADULTS, INC. (COSAC)

123 Franklin Corner Rd., Suite 215
Lawrenceville, NJ 08648
1-800-4AUTISM (in NJ) or
(609) 895-0190

COSAC

The **Autism Helpline** is operated by The NJ Council of Organizations and Schools for Autistic Children and Adults. The Helpline is **toll free** to N.J. residents by calling **1-800-4AUTISM** and is operational from **8 A.M. to 5 P.M., Monday through Friday.**

Suggested Readings From the NSAC Bookstore

#R-2	***Children Apart*** *Wing*
#26	***Early Childhood Autism*** *Wing*
#27	***Autistic Children: A Guide for Parents*** *Wing*
#144	***Autism in Adolescents and Adults*** *Schopler / Mesibov*
#145	***The Effects of Autism on the Family*** *Schopler / Mesibov*
#146	***Communication Problems in Autism*** *Schopler / Mesibov*
#1	***Autism: A Reappraisal of Concept and Treatment*** *Rutter / Schopler*
#130	***Teaching Developmentally Disabled Children: The Me Book*** *Lovaas*
#131	***Educating and Understanding Autistic Children*** *Koegel*

For more information about these books, or to place an order, call the NSAC Bookstore at (202) 783-0125